

APPENDIX 2

Were You Born Between

1938 and 1971

Or Pregnant Then?

If So, You Could

Be Exposed To

DES

National Cancer Institute

National Institute of Child Health and Human Development

National Institutes of Health

WHY YOU SHOULD LEARN ABOUT DES

DES is a drug that was given to millions of pregnant women primarily from 1938 to 1971. If you could have been exposed to it if you were born between 1938 and 1971 and your mother took prescription drugs while she was pregnant with you or if you took prescription drugs during a pregnancy during those years. If you were exposed to DES, you may need special health care, even if you have no health problems. This brochure presents an overview of DES exposure, and tells you how to get more information.

DES BASICS	
The drug: DES (Di-ethyl-sul-bes-trol)	
Kind of drug: Synthetic hormone	
When given: Primarily between 1938 and 1971	
To whom: An estimated 4.8 million pregnant women in the U.S.	
By whom: Private doctors and medical clinics in the United States, on U.S. military bases around the world, and in many foreign countries	
Reason given: To prevent miscarriage and improve pregnancy outcomes; eventually determined to be ineffective	
How given: Under more than 200 brand names as pills, injections, or vaginal suppositories, and sometimes in pregnancy vitamins	
Who may be exposed: Any woman who received medication during a pregnancy primarily between 1938 and 1971, and the child she was carrying may be DES-exposed	
When stopped: The FDA directed doctors not to prescribe DES to pregnant women in 1971 when it was linked to a rare vaginal cancer in DES daughters	
Signs of exposure: Usually no obvious signs	

HOW TO FIND OUT IF YOU WERE EXPOSED

If you were born between 1938 and 1971, ask your mother (or other relatives who might know her pregnancy history) if she took any medications during her pregnancy. Or if she had any problems such as bleeding, miscarriage, premature birth, or labor. Find out if your mother can get her medical records for what she took DES. If not, perhaps you can. If you can't find out how to get medical records by calling the DES hotline, alert to you on a DES overview information page 13 and 14.

DES DAUGHTERS

You are a DES daughter if your mother took DES while she was pregnant with you. ⁵² DES daughters have an increased risk for pregnancy problems, a rare form of vaginal cancer (clear cell cancer) and possibly infertility. ⁵² All DES daughters need special medical care beginning in the first weeks of pregnancy, even if they have already had children. ⁵² DES daughters of all ages should get the recommended pelvic exam annually. ⁵² Remember, early detection of cancer saves lives. ⁵²

WHAT TO DO
<ul style="list-style-type: none"> Find out if you are DES exposed (see page 3)
<ul style="list-style-type: none"> Tell your doctor that you are (or may be) DES-exposed, and become familiar with the possible risks.
<ul style="list-style-type: none"> Get the recommended pelvic exam for DES daughters (described on page 6) annually
<ul style="list-style-type: none"> Practice monthly breast self-examination. Get a regular mammogram every one to two years beginning at age 50. Before that, discuss your breast cancer risk with your doctor to develop a program for breast cancer screening.
<ul style="list-style-type: none"> Get the medical care recommended for DES daughters during pregnancy.
<ul style="list-style-type: none"> Also, for a second opinion from a doctor experienced in caring for DES daughters whenever any surgery on the vagina, cervix, fallopian tubes or uterus is recommended.



RECOMMENDED PELVIC EXAM

The recommended pelvic exam for DES daughters of all ages is one of a different kind for non-exposed women. The correct exam always includes:

- A careful visual inspection and gentle palpation (feeling) of the entire vagina.

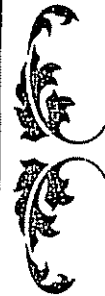
- Separate Pap smears from the cervix and from the surfaces of the upper vagina.

- A bimanual exam (the examiner feels the uterus, tubes, and ovaries with the fingers of one hand inside the vagina and the other hand on the abdomen).

An exam may also include:

- Iodine staining of the vagina and cervix (normal tissue stains brown).

- Depending on the results of these tests, further procedures may be necessary, such as colposcopy and biopsy.



PREGNANCY

With proper care, most DES daughters can have successful pregnancies. If you are a DES daughter and you are pregnant, be sure to:

- Get your medical care from someone who is familiar with the care of women at higher risk for pregnancy problems.

- Tell your doctor that you are DES-exposed.

- Contact your doctor as soon as you suspect you are pregnant. You should be examined right away to determine whether the pregnancy is in the uterus.

- Learn the signs of ectopic (tubal) pregnancy and premature labor.

- Visit your doctor at frequent intervals throughout your pregnancy. He or she will suggest a schedule that is right for you.

